

South Dakota Alzheimer's Disease and Related Dementias Needs Assessment

A report for the South Dakota Alzheimer's Disease and Related Dementias Work Group.

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Process Overview

Maximizing Excellence, LLC (MELLC) was contracted to provide the Alzheimer's Association South Dakota Chapter the expertise needed to facilitate the development of a South Dakota Alzheimer's and Related Dementias (ARD) State Plan. The following objectives were set for MELLC to accomplish that work:

1. Formalize the South Dakota ARD State Plan Work Group.
2. Conduct a statewide needs assessment.
3. Create a comprehensive summary report to enlighten the development of a state plan.

History:

South Dakota is one of four states without an ARD state plan. Need for a state plan was identified in 2015 by Alzheimer's Association South Dakota Chapter leadership. State plans have typically been pursued in one of two ways: 1) through grass-roots efforts; or 2) through a state sponsored task force. When the issue was brought before the South Dakota State Legislature during the 2016 session, it was determined that an ARD state plan would best be founded through a non-legislative work group with guidance from the Alzheimer's Association South Dakota Chapter.

Objective 1: Formalize the South Dakota ARD State Plan Work Group

The South Dakota ARD State Plan Work Group formally convened in April 2017. The voluntary work group is comprised of 21 individuals determined to create a state plan that will work to meet needs, fill gaps in resources and services, and improve the overall quality of ARD care in South Dakota for individuals living with the disease and their caregivers.

Criteria for work group selection included proximity to and experience with ARD, degree of influence and/or expertise in the field, and commitment to seeing the work through. The work group met four times between April 2017 and February 2018. Members were tasked with contributing their experience with and perspective of ARD, reviewing and approving methodology and materials, and ultimately engaging in state plan development under close guidance of the South Dakota ARD needs assessment.

Work Group Roster

Dr. James Barker	Brandy Fiala	Molly Keegan
Dean Bertsch	LaVonne Gaspar	Leslie Morrow
Dr. V.R. Brandenburg	Nathan Gelhaus	Secretary Gloria Pearson
Dr. David Brechtelsbauer	Lisa Griffin	Edith Renner
Dr. Oluma Bushen	Tom Herges	Brad Richardson
Holly Carr	Kathi Herreid	Jennifer Rosen
Peggy Cruse	Lori Hintz	Diana Swier

Work group members represent health care providers and administrators, advocacy organizations, state agencies, and family caregivers.

Process Overview

Objective 2: Conduct a statewide needs assessment.

Comprehensive needs assessments are at the core of a state's ability to effectively use information to develop, implement, and maintain state plans. The data gathered and presented is specifically related to ADRD in South Dakota, making for a focused data set to inform action and policy.

Planning

During the planning phase, the work group set priorities and goals to make sure the needs assessment would be a representative snapshot of ADRD in South Dakota. The work group sought to gather and present information that would bring about new findings, update existing ones, and confirm "what we know to be true." They were also interested in finding out what potential solutions would work best for South Dakota.

The following priorities and goals guided needs assessment development:

- Current availability, accessibility, affordability, and quality of services and resources.
- What availability, accessibility, affordability, and quality should look like.
- Gauge awareness of ADRD at all levels, including any stigma associated with ADRD.
- The adequacy of education and training available for anyone associated with ADRD.
- How ADRD is experienced by those living with it or working with it, and how that experience can be improved.

The Alzheimer's Association Needs Assessment Toolkit and existing ADRD state plans outside of South Dakota were also referenced during planning.

Methodology

The needs assessment is based on a mixed-methods approach comprised of three key inputs:

1. Focus groups facilitated throughout South Dakota.
2. Online statewide needs assessment survey.
3. Secondary data collection and analysis.

Input 1 | Statewide focus groups

Focus groups sites were mapped out to be inclusive of both the urban and rural experience of South Dakota residents. The state's population of nearly 860,000 was divided into five regions based on its 35 legislative districts. Each region represented between six and eight districts and between 120,000 and 200,000 people. The regions were also constructed with points of common experience in mind, such as urban vs. rural and proximity to major health care institutions. Three focus groups were held in each region, totaling 15 focus groups in 13 cities and towns.

A purposive sample was sought by creating invitation materials—flyer, ad, and news release—that explicitly stated what the focus groups aimed to do and who the ideal participant would be. A connection to ADRD, either personal or professional, was set as a condition of participation. An outreach strategy was created to ensure the invitations reached as many ideal participants as possible through established media resources and direct outreach by work group members. South Dakota legislators were invited via letter.

Process Overview

The 90-minute focus groups were held on weekdays either over the lunch hour or early evening to accommodate participant schedules. A light meal was offered to thank participants for their time. Registration was capped at 20 for each session.

Focus groups were purposed with collecting firsthand accounts of what ADRD looks like in South Dakota. A set of 12 questions was developed to gather the stories and emotions that would make for a compelling case for statewide attention and action. Participants were asked to identify their needs and barriers, share their definitions of support and quality, and share their recommendations for improving the care of someone living in South Dakota with ADRD. In total, 147 South Dakota residents attended a focus group.

Input 2 | Statewide needs assessment survey

An online statewide needs assessment survey was designed to a) complement the qualitative data of the focus groups; and b) reach a larger segment of the state's population. Sampling methods included purposive and convenience techniques. A purposive survey sample was sought by putting the survey in front of individuals with an established connection to ADRD either through the Alzheimer's Association South Dakota Chapter or through the professional and personal networks of work group members. All focus group participants were encouraged to complete the survey. The survey was available via an online link or paper copy to these respondents.

Convenience sampling took place through the circulation of paper surveys to places that those touched by ADRD might frequent, such as support groups, church groups, and rural health care clinics.

The 17-question survey included open-ended and closed-ended questions. Respondents were asked to identify the three most pressing needs of persons impacted by ADRD in South Dakota, rate the quality of ADRD care, and share their recommendations for improving care. In total, 1,025 South Dakota residents completed the needs assessment survey.

Input 3 | Secondary data collection and analysis

Secondary data provided an analysis of indicators for South Dakota, including population projections, social and economic factors, prevalence, health care workforce, and caregiving. An inventory of long-term care providers in South Dakota was included. Additional data sources were contributed to help frame the report. All data was housed in a database with the intent for it to be updated and used to support the state plan ongoing.

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Objective 3: Create a comprehensive summary report to enlighten the development of a state plan.

MELLC developed survey and focus group content as well as accompanying distribution materials. MELLC conducted the statewide needs assessment survey and facilitated fifteen focus groups throughout the state. SLM Consulting, LLC collected and analyzed secondary data to support primary data findings. MELLC merged the three data sets to create a comprehensive statewide needs assessment report. Alzheimer's Association South Dakota Chapter and the work group provided technical support throughout the process and were the recipients of the report. The report will be the catalyst for developing a comprehensive state plan. The state plan will be presented to the South Dakota State Legislature in hopes of receiving their support for the critical work to be done.

Limitations

Given the urgency of developing a state plan on ADRD, the timeline to complete the needs assessment was aggressive to allow the work group 12 months to develop a state plan informed by the findings and time to prepare their appeal to the South Dakota State Legislature during the 2019 session, which runs January – mid-March. After consulting with those well-versed in tribal community study inclusion, it was determined that the timeline did not allow for tribal communities to be purposefully included in the study outside of the study's broad participant recruitment strategies. Project leadership pledged to involve this perspective and amend the report by the end of 2018.

Special contribution

Work group member James Barker, MD sought to include the poor or uncared in the study. He designed a questionnaire that involved five basic questions about ADRD and administered it verbally to 20 people at the Bishop Dudley Hospitality House. From their responses, he provided the following generalizations:

1. Most of them knew someone who had some form of ADRD.
2. No one had been a personal caregiver for anyone with ADRD, though they know or had a relative who had been.
3. They did not know of the related problems in the caregiver's position.
4. They had not any suggestions for how state or local services could have made the situation better.

He concluded with acknowledging individuals without a place to sleep or roof over their heads are often not selected to be caregivers and are unlikely to think of organized system solutions that can help their friends or family.

With that said, he believes that the recommendations of the state plan will help these individuals and their family members who may now, or in the future, suffer from ADRD and need the coordinated and high quality of state services that will be advocated in the plan.

Participant Overview

147 | focus group participants

Participants per region

58 | Region 1—Sioux Falls and Brandon

24 | Region 2—Rapid City and Spearfish

15 | Region 3—Pierre, Chamberlain, and Mobridge

19 | Region 4—Mitchell, Yankton, and Vermillion

31 | Region 5—Aberdeen, Brookings, and Watertown

**Focus groups averaged 10 participants per session.*

1,025 | survey respondents

The respondent base is shaped by the following points:

→ General demographic information:

- 95.6% | white.
- 79.0% | female.
- 60.0% | represent 5 of 66 counties (Minnehaha, Pennington, Lincoln, Brown, Fall River)
- 67.0% | between 45 and 74 years of age.
- 61.9% | employed full-time.
- 58.0% | household income between \$50,000 and \$149,999.
- 36.6% | health care providers.

→ Specific points related to ADRD:

- Primary connections to ADRD.
 1. 43.0% | son, daughter, or other family member of a PWD.
 2. 33.4% | currently work or have worked with PWD.
- Secondary connections to ADRD.
 1. 42.5% | Know or have known a PWD.
 2. 25.7% | Friend or acquaintance of a PWD.
- 58.1% | have either been a family/friend or professional caregiver.
- 69.3% | familiar or somewhat familiar with ADRD care and resources in SD.

It is reasonable to assume these points are representative of the total needs assessment sample.

Glossary of Terms*

ADRD: Alzheimer's Disease or Related Dementias.

Assisted Living center: Licensed by the state to provide personal care and services beyond basic food, shelter, and laundry. May admit and retain only those who do not require more than intermittent nursing care by a licensed nurse. May provide home health agency services for short term skill services for a specific medical reason.

Caregiver: Anyone who provides care to a person with Alzheimer's disease or related dementias. Caregivers can be family members, friends, or paid professional caregivers. Caregivers may provide full or part-time help to the individual with dementia.

- Paid professional caregivers work in hospital, residential, and home settings. Depending on the level of care provided, they are direct care providers or professional practitioners.

Chronic disease: According to the U.S. National Center for Health Statistics, a chronic disease is one persisting for a long time (usually three months or more) and generally cannot be prevented by vaccines or cured by medications, nor do the symptoms disappear on their own. Health-damaging behaviors—particularly tobacco use, lack of physical activity, and poor eating habits—are major contributors to chronic disease.

Dementia: Dementia is not a specific disease. Instead, dementia describes a group of symptoms associated with a decline in memory, thinking, and social abilities severe enough to reduce an individual's ability to perform everyday activities. Alzheimer's disease is the most common type of progressive dementia in older adults, yet there are several types of dementia.

Geriatricians: Physicians concerned with the diagnosis, treatment, and prevention of disease in older adults. They specialize in managing conditions specific to aging, including dementia.

Guardian: Guardianship is established by a court order. The court grants the guardian authority and responsibility to act on behalf of another person. The relationship is fiduciary, which means that the guardian is obliged to act in the best interest of the individual for whom he/she is a guardian.

Home health agency: certified by Medicare to provide nursing services in the home to persons who require intermittent nursing care.

Hospice: A hospice program offers support for dying individuals and their family members to live as fully and comfortably as possible. Hospice care is generally provided to individuals with a life expectancy of six months or less. Rather than seeking a cure, hospice care aims to make an individual's remaining time as comfortable and as meaningful as possible. Hospice is a Medicare benefit.

Long-term care facility: A long-term care facility is a nursing home or assisted living center designed to provide a variety of services, including both medical and personal care, to individuals who are unable to manage independently in the community. Many residents in long-term care facilities have dementia.

Glossary of Terms* *continued*

Long-Term Services and Supports (LTSS): Provides home and community-based service options to individuals 60 years of age and older and 18 years of age and older with disabilities.

Medicaid: Medicaid is a joint federal and state program that helps with medical costs for qualified individuals with limited income and resources. Medicaid can also provide benefits not normally covered by Medicare, including long-term nursing home care and personal care services.

Medicaid waiver: States can use the waiver process to test new or existing ways to deliver and pay for health care services in Medicaid and the Children's Health Insurance Program (CHIP). There are four primary types of waivers and demonstration projects, one of which is the Section 1915(c) Home and Community based Services Waiver.

Medicare: Medicare is a federally-funded government health insurance program for people aged 65 and older and for certain younger individuals with disabilities.

Nursing facility: Licensed by the state; may be certified by Medicare and/or Medicaid. May admit and retain those who require nursing care by licensed nurses. Have a medical director and staffed with licensed nurses.

Palliative care: Palliative care includes medical and/or surgical methods to ease the pain and other distressing symptoms of a serious or incurable illness.

Person-centered care: This term refers to health care and social services designed to reflect the individual's unique preferences, values and needs, identified and agreed upon in partnership with the medical providers, the patient, and other family members when appropriate. The goal is for people to be treated as individuals and to receive appropriate and timely care that meets their needs.

PWD: Person or people living with a dementia.

Respite care: Respite care provides a caregiver temporary relief from the responsibility and stress of caring for individuals with chronic physical or mental disabilities. Examples of respite care include in-home assistance, a short or long-term care facility stay, or day care programs for adults.

Rural and frontier communities: For the purposes of this plan, rural communities in South Dakota were those with a total population of less than 25,000.

Urban communities: For the purposes of this plan, urban communities in South Dakota were those with a total population of more than 25,000 and/or with full-service hospitals and hospital staffs with multiple specialists. Criteria considers Brookings, Mitchell, Rapid City, Sioux Falls, Watertown, and Yankton to be urban communities.

**In part adopted from Montana's ADRD State plan.*

ADHD South Dakota Needs Assessment Executive Summary

The needs of people living in South Dakota with dementia (PWD) and those that care for them—whether in a professional or personal capacity—are not being fully met. Frustration exists throughout the entire ADRD community as to how dementia is handled in the state and participants have not been satisfied with the services and resources offered to them.

Participants shared they thought more factors were working against the best interests of PWD than for them. Their collective experience can be summed up into two key takeaways:

1. Services and resources are inadequate or missing throughout the state.

- South Dakota's moratorium on nursing home beds does not allow nursing home facilities to consolidate or add more beds in sites that have already met their quota. Participants believe the moratorium prohibits adding beds where they are most needed.
- Assisted living and nursing homes with memory care units exist, but not on the scale that is needed to meet growing demand. Many participants have had to relocate to access memory care or settle with non-specialized care in their area.
- Limited services and resources exist for higher-acuity or higher-care need PWD. Behavioral health and crisis intervention is virtually nonexistent. The only option for many participants was the Human Services Center (HSC) in Yankton as many long-term care facilities evict or do not accept these PWD, leaving families with few options.
- Access to services and resources is significantly compromised in rural and small communities. Getting connected with primary care, specialty services, transportation, workforce, care facilities, caregiver support, funding, and education was reported as difficult and discouraging.
- Caregivers cannot find the respite care, support groups, education, training, and continuous guidance they need to navigate their journey with the disease to the best of their ability. This was reported as a barrier for family members trying to access the appropriate level of care to keep their loved one at home longer and extend their quality of life. Caregivers consistently reported not knowing where to go or how to access care and support.
- Mandatory and/or standardized ADRD education and training is not in place for professional caregivers. Professional caregivers, and those that employ them, raised concern at their competency to meet the needs of patients and families. Family members shared many accounts of professional caregivers mishandling cases, attributing it in part to a lack of training. They also shared that having trust in the ability, knowledge, and quality of their care providers is of greatest value (and concern) to them.
- Training and education is not prioritized amongst indirect care professionals, including financial and legal advisors, police, and emergency medical technicians (EMTs). Without this expertise in place, decisions are often not made in the best interest of the PWD and their family.

ADHD South Dakota Needs Assessment Executive Summary *continued*

2. Where services and resources exist, they are constrained by high costs, insufficient workforce numbers, a lack of knowhow, and debilitating stigma.
 - Memory care is more expensive for facilities to provide, and for a family to afford, than standard nursing care. Participants reported being forced to place their loved ones in long-term care facilities regardless of memory care needs due to affordability and a Medicaid reimbursement rate that works against having memory care as a viable option for the majority. Most memory care is private pay, which has priced out many participants from accessing it. For some participants, their only affordable care option was to spend down their assets to qualify for Medicaid.
 - Long-term care facilities that offer memory care are not required to accept Medicaid residents. And participants have found that these facilities typically limit the number they do accept. The Medicaid reimbursement rate for long-term care facilities, especially small facilities, offers a low return for memory care and does not account for the heightened costs associated with memory care, including a lower staff to resident ratio, continuing education for staff, a non-mixed population, and increased security.
 - PWD are placed in settings that are ill-equipped for higher-needs residents due to reluctance to seek a diagnosis, delay of an accurate diagnosis, and lack of knowhow on how to navigate services and resources for PWD. Assisted living facilities and home health agencies have been found too late in disease progression.
 - There are not enough direct care workers for ADRD service and resource providers to adequately staff their operations. Difficulty in finding and retaining qualified staff—above and beyond quantity—compounds the issue. Participants believe statewide workforce development, and the pay scale of CNAs, are at the heart of the issue.
 - The training and education that does exist does not adequately prepare care providers. This includes the baseline of what ADRD is, to the more complex—handling behaviors, crisis response, medication management, and therapies. Participants see provider proficiency on these topics leading to better coordination amongst services, more consistent quality, and improvement in how ADRD is approached in health care.
 - Participants reported that being a family caregiver is financially straining, and emotionally and physically difficult to endure. 77% of survey respondents were somewhat to not familiar with available services and resources, and no one majority point of access to information was identified. Access to adult day services and home health to ease such stressors are limited by few available options, and caps on the number of hours a caregiver can receive financial assistance to utilize the service. Caregiver support groups are hard to keep active in small communities.
 - ADRD is met with significant stigma throughout South Dakota. It is not something people are comfortable talking about or seeing, and therefore participants have seen PWD pushed to the periphery of society. It was reported that stigma stops people from accessing care, seeking support, and discourages PWD and their caregivers from staying engaged in community life.

ADHD South Dakota Needs Assessment Executive Summary *continued*

The needs assessment uncovered many gaps but also shed light on areas that participants have seen improvement and/or effectiveness:

- The value of memory care on a PWD's quality of life is being more widely accepted and endorsed.
- Trained professional caregivers have increasingly demonstrated a person and family-centered care approach, treating PWD with dignity, spending one-on-one time with them, and incorporating personalized activities and family suggestions into care plans.
- Churches and faith circles have been reliable sources of support and community engagement.
- The Alzheimer's Association South Dakota Chapter is the most visible advocate for PWD and their caregivers and is where participants reported going first for information.
- Participants rated the quality of ADRD care as good for hospice care, home health care services, adult day services, primary care involvement, non-physician health care professionals, auxiliary services, long-term care facilities, and community initiatives.

Care for ADRD is not *what* it needs to be or *everywhere* it needs to be in South Dakota for people living with and amongst the disease to have their best outcome possible. Participants did not see this as a reality unique to South Dakota, but as a real struggle for the country. They were encouraged to learn that other states have taken the initiative to improve the care of PWD through state plans. Participants believe that crafting a plan to meet the needs of South Dakota, while long overdue, is the right next step.

Needs assessment participants did not claim to have all the solutions but did share many common recommendations for improving the state of ADRD care in South Dakota based on the breadth and depth of their collective experience. They are hopeful at the prospect of a state plan and see it as a road map and convener of influence, advocacy, and action.

| Top Five Recommendations

Recommendations for improved ADRD care in South Dakota align with the following priorities:

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.
2. Develop funding priorities and strategies to make ADRD services /resources more affordable -for facilities to provide and -for families to access.
3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.
4. Prioritize the education and training of professional care providers to improve care quality and efficiencies. Provide training opportunities to family caregivers.
5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

A detailed analysis of these recommendations can be found on pages 16-32.

Rationale for a South Dakota ADRD Plan

78.4% of survey respondents reported being concerned to very concerned about how ADRD could affect themselves or their loved ones someday.

This concern is driven in part by being closer to, or more aware of, the impact of ADRD than the average South Dakotan. 76.4% of respondents shared a primary connection of either being a son, daughter, or other family member of a person with dementia (PWD) or having worked with PWD in a professional capacity. Nearly 65% identified as a family member, friend, or professional caregiver to a PWD.

Personal concern was scaled to statewide concern when focus group participants defined the need for a state plan based on:

1. Increasing prevalence of ADRD in South Dakota.
2. Increasing aging population in South Dakota.

1. Increasing prevalence of ADRD in South Dakota

As one participant said, *"Everyone is going to be touched by ADRD in some way."* Participants foresee an increase in the amount of ADRD cases diagnosed annually and with that, an increase in the number of people accessing care. Given their perception that ADRD care is already inadequate with the state's current rate of diagnosis, participants believe that to get ahead of the issue and assure care is available for all of those who will come to need it, ADRD needs to be addressed at the state level.

- 18,000 South Dakota adults, age 65 or older, are projected to have Alzheimer's Disease in 2020, with a projected number of 20,000 adults to be diagnosed by 2025; resulting in a 17.6% increase in prevalence from 2020 to 2025 (Alzheimer's Disease Facts and Figures Report, 2017).
- Alzheimer's Disease was the fifth leading cause of death among South Dakota adults from 2011-2015, as well as by race. It was the third leading cause of death in adults aged 80-89 and the second leading cause of death in adults aged 90 and over (*South Dakota Department of health, Office of Health Statistics, 2015*).

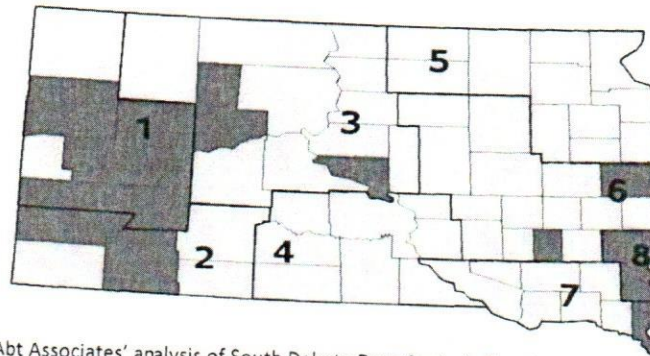
2. Increasing aging population in South Dakota.

Participants see South Dakota's aging population increasing every day as Baby Boomers age. They believe South Dakota's Baby Boomer population—born between 1946 and 1964—will only increase in coming years with an increase in transplant retirees attracted to South Dakota as a "best place to retire." As more South Dakotans live longer, participants recognize their health care needs will increase. With an increase in the prevalence of ADRD and an increase in the majority age demographic (65+) most likely to be diagnosed with ADRD, a state plan on ADRD is deemed necessary to *"take care of our own."*

- The South Dakota population 45 years of age and older is projected to increase from 356,306 in 2015 to 435,595 in 2035. Those 65 years of age and older are projected to increase from 139,749 in 2015 to 227,225 in 2035 (*Department of Sociology and Rural Studies, SDSU, 2012*).
- Life expectancy in South Dakota is 82 years of age for females and 77.2 for males. From 1990 to 2016 the population 85 years and older has increased by approximately 7,000 persons (*Institute for Health Metrics and Evaluation, 2016*).

Rationale for a South Dakota ADRD Plan

South Dakota counties where the elderly disabled population is expected to double from 2010 to 2035: Brookings, Butte, Custer, Hanson, Hughes, Lincoln, Meade, Minnehaha, Oglala, Lakota, Pennington, Union, and Ziebach.

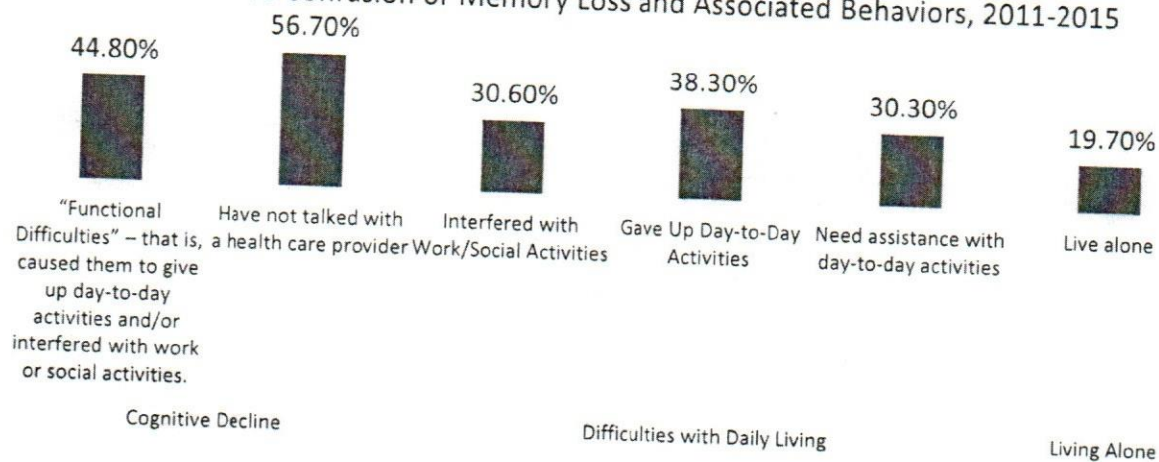


Abt Associates' analysis of South Dakota Data Center's Population Projections data.

Confusion and memory loss in South Dakota

- 15% of South Dakota adults had a primary diagnosis of Dementia in 2017. (*Alzheimer's Facts and Figures, 2017*)
- 6.3% of older adults 65 years or older, reported increased confusion or memory loss that is happening more often or is getting worse in the preceding 12 months. 39.1% of older adults 65 years or older, who have experienced increased or memory loss who reported their confusion or memory loss interferes with their ability to engage in social activities or household chores. (*BRFSS, 2015, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Healthy Aging Data*)

% of South Dakota Adults, age 45 and older, Who Have Experienced Increased Confusion or Memory Loss and Associated Behaviors, 2011-2015



Snapshot of ADRD care in South Dakota

Satisfaction with ADRD services and resources

Scale of 1-5, 5 being very satisfied

2.9	Information about and guidance in finding services and resources upon and beyond diagnosis
2.9	Quality of services and resources
2.8	Education and training of health care professionals and caregivers
2.7	Services and resource available in your area
2.7	Public awareness
2.6	Community support for family and non-family caregivers of persons with ADRD
2.3	Coverage of costs of services and resources

Quality of ADRD care

Scale of 1-5, 5 being excellent

4.3	Hospice care
3.9	Home health care services
3.9	Adult day services
3.7	Non-physician health care professional
3.6	Auxiliary services (drug treatment, behavioral health, etc.)
3.6	Assisted/long-term care facilities
3.6	Primary care/family doctor involvement
3.5	Community based initiatives (transportation, public service preparedness, etc.)

Snapshot of ADRD care in South Dakota *continued*

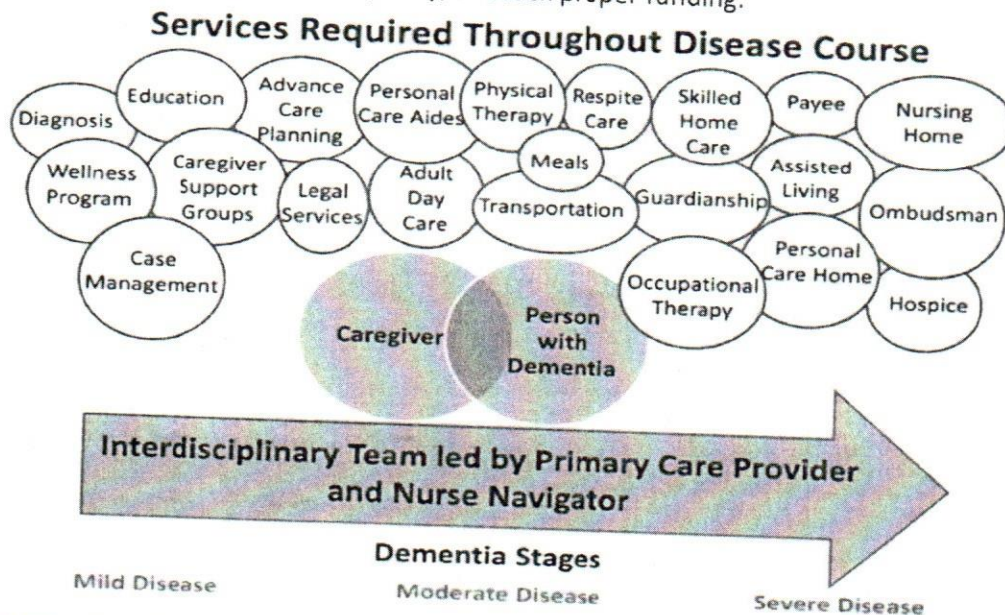
Most pressing needs

932 survey respondents weighed in on what the three most pressing needs for persons in South Dakota impacted by ADRD.

1	Coverage of costs for services and resources	55.7%
2	Information about and guidance in finding services and resources upon and beyond diagnosis	55.0%
3	Services and resources available in your area	52.9%
4	Education and training of health care professionals and caregivers	43.2%
5	Quality of services and resources	40.5%
6	Community support for family and non-family caregivers of PWD	36.7%
7	Public awareness of the disease	10.9%

Vision for ADRD care

Participants painted a broad picture of all the services and resources involved in a PWD's and their caregiver's experience across three present but hard to discern stages of dementia. An interdisciplinary team leading both parties through a continuum of care was desired and seen as best practice. As it stands in South Dakota, many of the services displayed are uncoordinated, inconsistent in quality, and lack proper funding.



Adopted from Montana's Alzheimer's and Dementia State Plan, 2016.

Meeting the Needs of PWD and their Caregivers

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1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Rural and urban settings

57% of the population in South Dakota live in urban areas, while 43% of the state's population lives in rural areas. The majority of South Dakota's 66 counties are designated as rural or frontier. (*Decennial Census 2010, South Dakota*)

Participants spoke often of the rural-urban divide and the disparity in services and resources between the two was articulated when participants were asked to list what is available and missing in their community for ADRD care. The divide was identified as a source of difficulty for the state plan to address due to how similar the needs of the two populations are but how different service and resource delivery looks like for each.

Services and resources = comprehensive care

Improving the care of PWD in South Dakota requires that all residents have access to a comprehensive suite of services and resources, ideally presented within a continuum of care framework. Participants are not satisfied with the services and resources available to them in their area. As one participant said, it should be a priority to have *"the right care available to the right person at the right time."*

The following reflects how participants define comprehensive care for a PWD:

- Long-term care facilities:
 - Assisted living, preferably with memory care.
 - Skilled nursing, preferably with memory care.
 - Hospice.
 - Home health care.
- Health care supports and auxiliary services:
 - Care providers: primary care, mental and behavioral health, geriatricians, etc.
 - Access to ADRD expertise for diagnosis, treatment, and navigation.
- Caregiver supports:
 - Alzheimer's Association.
 - Respite care.
 - Ombudsman advocate.
 - Support groups for PWD and caregivers.
 - Adult day services.
- Community supports:
 - ADRD-friendly public spaces.
 - ADRD-aware representatives from professions that work with PWD and their families, including emergency, financial, legal, and retail services.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Long-term care in South Dakota

According to the 2017 AARP state scorecard on long-term services and supports, South Dakota needs to improve its long-term care options for residents. The national scorecard measures the care available in states based on accessibility, choice, and quality. It also assesses their support for family caregivers and the transitions between health facilities and home. South Dakota ranks 32nd overall. The state ranks lowest in the categories of effective transitions and choice of setting for care.

Needs assessment participants rated the quality of long-term care facilities a 3.6, on a scale of 1-5, with 5 being excellent. Quality could be improved with increased consistency and quality assurance amongst care experiences and facilities, and facilities that are designed to respond to the unique needs of ADRD residents.

For many, quality of care is second to what is available. When memory care in a long-term care facility is not an option, participants reported having to place PWD in general population facilities, which are not designed with ADRD symptoms in mind. Participants also spoke of difficulty in transitioning between care settings. Without a continuum of care guiding these transitions and a lack of direction from providers, participants reported PWD staying longer than they should in assisted living facilities and not being able to find nursing facilities with open memory care beds or general population beds close to home when the time comes. Home health was not a common option amongst participants and was not a top recommendation given by physicians when discussing care plans with caregivers.

As stated by the South Dakota Department of Health, the levels of institutional care in South Dakota include nursing facilities, assisted living centers, adult foster care homes, residential living centers, congregate housing, and home health services.

Assisted living facilities	171
Skilled nursing facilities	109
Home health agencies	43
Residential living centers	36
Hospice options	25
Adult foster care homes	15
Congregate housing	X

Department of Health Provider List, 2017.

Nationally, ADRD is most prevalent among nursing home residents (50.4%). 44.7% of hospice residents, 39.6% of residential living centers, and 31.4% of home health have a diagnosis of ADRD. It is least prevalent among adult day services center participants (29.9%). Over 75% of long-term care facilities do not solely serve PWD or offer an ADRD unit.

CDC/NCHS, National Study of Long Term Care Providers, 2014)

South Dakota ranked 16th for available assisted living beds in 2010, at 3.4 available beds per 100 elderly individuals. The state continues to have the 2nd fewest Medicare skilled home-health episodes, with just over 5 episodes per 100 elderly individuals.

Existing state long-term care capacity was judged insufficient to meet the coming demand, with nursing homes needing to be replaced and rebalanced, and assisted-living capacity, home health care services, and home and community-based services (HCBS) additionally requiring expansion.

ABT Associates Evaluating Long-Term Care Options for South Dakota, Update 2015.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Health care supports and auxiliary services

Participants rated the quality of primary care physicians, non-physician health care professionals, and auxiliary services as good. However, they rated their satisfaction with services and resources available in their area as less than satisfactory and identified having more services and resources available as a pressing need for South Dakota.

Disparity in access to health professionals and medical services exists. Shortages are geography and income based.

- Across South Dakota's 66 counties, there are 47 medically underserved areas.
- 24.4% of the state's population lives in a health professional shortage area.
- As of January 2017, South Dakota has 200 health professional shortage areas—87 primary care and 49 mental health. The rate of primary care physicians per 100,000 population is 85.3; it is 183 for mental health providers.

SOUTH DAKOTA MEDICALLY UNDERSERVED AREAS/POPULATIONS
January 2017



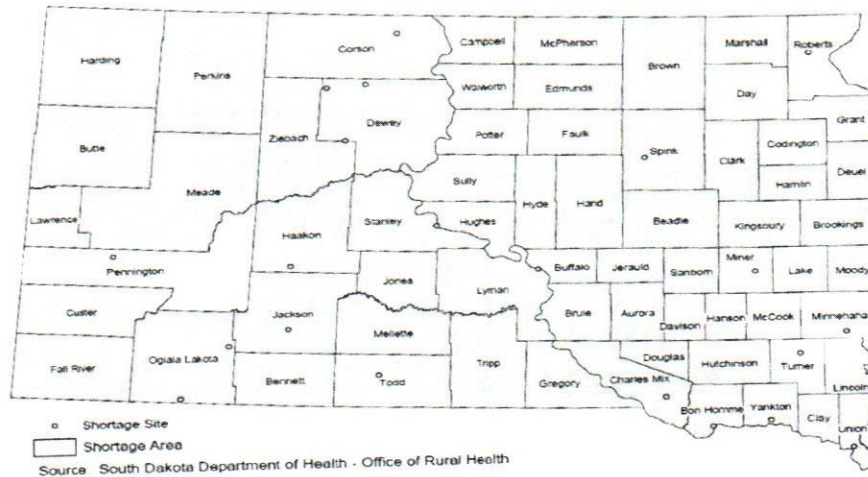
Participants report that limited access to health professionals and medical services negatively affect the quality of life a PWD and their caregiver experiences.

Participants living in underserved and shortage areas reported having to travel more than one hour and up to three for appointments that usually necessitate follow-ups. This frequency of travel is difficult to schedule for family caregivers who maintain employment and can agitate a PWD, as they thrive with consistency in settings. Even when placed in a residential setting, PWD are not guaranteed access to physicians or needed specialists because they often do not provide in-person or telemedicine consultation to facilities, resulting in required travel.

It is hard to find the right doctor to diagnose AD/DR in South Dakota. Long wait times to see physicians who are generally not well versed in the different types of dementia typically leads to a string of referrals, delaying proper diagnosis far past onset and acknowledgement of symptoms.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

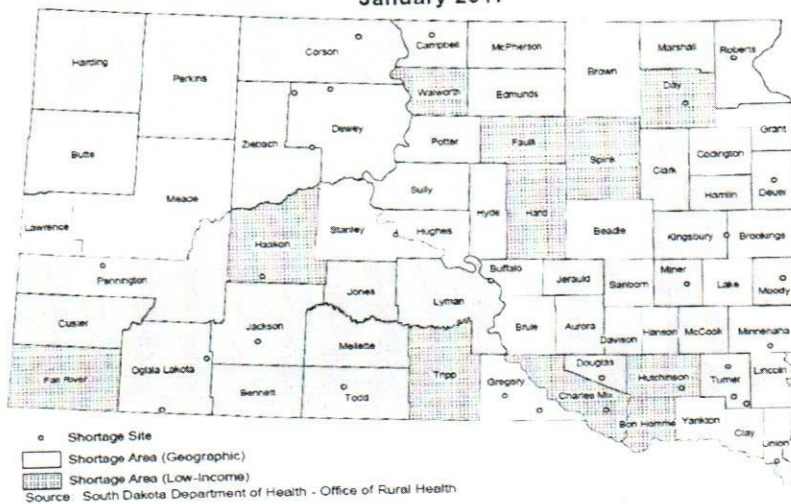
**SOUTH DAKOTA HEALTH PROFESSIONAL SHORTAGE AREAS
MENTAL HEALTHCARE
January 2017**



Participants do not think PWD are provided the mental health care they need. Their loved ones have been admitted to the Human Services Center because the mental health care available in the community or in a residential facility was either nonexistent or ill equipped to manage the behavioral health issues of ADRD.

Undiagnosed PWD have been sent to jail because first responders do not know how to identify the behavioral symptoms of ADRD. Treatment with medication can take away what was left of their family member's personality. Participants see maltreatment of PWD directly linked to a lack of mental health care and an overall lack of proper crisis management—not having Plan B.

**SOUTH DAKOTA HEALTH PROFESSIONAL SHORTAGE AREAS
PRIMARY MEDICAL CARE
January 2017**



Many participants have entrusted the care of PWD to non-ADRD physicians.

They have found it difficult to find and access ADRD experts or elder care experts, such as geriatricians.

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Caregiver supports

Nearly 65% of needs assessment participants—survey and focus groups—identified with being a family or professional caregiver for a PWD. Caregivers see themselves as primarily responsible for the wellbeing of PWD, more heavily involved in daily care than physicians, and carrying the voice of their loved ones and patients forward. Research supports this perception by asserting that family caregivers will provide the majority of hands-on care to PWD and that there is no practical alternative to the family caregiving workforce.

What family caregiving looks like in South Dakota...

- There are 43 million hours of unpaid care in South Dakota. Unpaid care in South Dakota is valued at \$4,385 (millions). (Source: *Alzheimer's Facts & Figures 2017*)
- Caregivers in South Dakota have higher health care costs at \$27 million. (Source: *Alzheimer's Facts & Figures 2017*)
- In 2015, \$770,572 was expended for caregiver's respite care in South Dakota. (Source: *Administration for Community Living 2017*)
- 1 out of 5 needs assessment survey respondents indicated that their full-time employment status has been influenced by their caregiver status.

Participants suggested that what is beneficial for a PWD is beneficial for a caregiver, and vice versa, because they are so intrinsically tied to—and dependent upon—each other's health and quality of life. Caregiver support was defined as quality care, emotional support, community awareness, care coordination, accessibility, and preparedness for disease progression.

Participants stated access to caregiver supports like adult day services and support groups can ease caregiver stress and provide cost-savings to families by keeping PWD independent and in their homes longer. They defined access to caregiver supports as knowing what is available in their community, how to get connected with those supports, and having flexible availability.

What participants said about the benefits of caregiver supports...

Adult Day Services

- Caregiving is very taxing—mentally and physically—without this service.
- Assist those that are trying to keep people at home longer.
- Gives a break to caregivers and facilities.

Support groups

- Opportunity for caregivers to not feel so alone and stay engaged.
- Share best practice helps people understand the stages of the disease the person is going through.

Adult Day Services and support groups are typically accessed through long-term care facilities and senior centers in South Dakota. It was reported that support groups are difficult to keep active in small communities. The state's Long-Term Services and Supports program is seen as a valuable program for administration of caregiver support but riddled with limitations on service area and use.

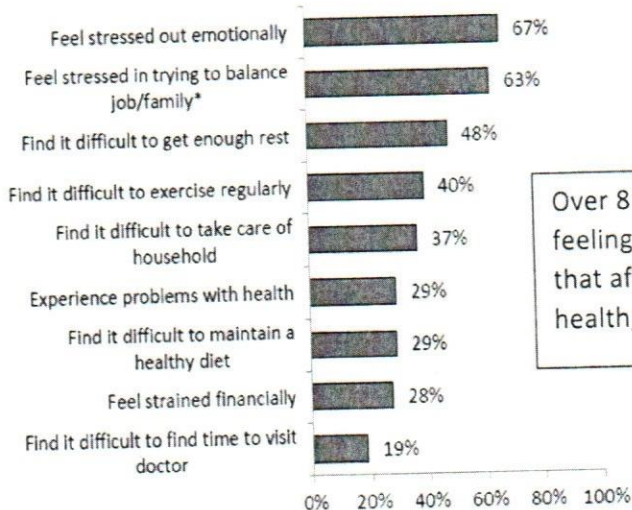
Other caregiver supports that surfaced included financial and legal preparation and planning, education and training, and the Alzheimer's Association South Dakota Chapter.

What family caregiving looks like in South Dakota (nonspecific to ADRD)

Findings from the AARP South Dakota Caregivers Survey, 2017

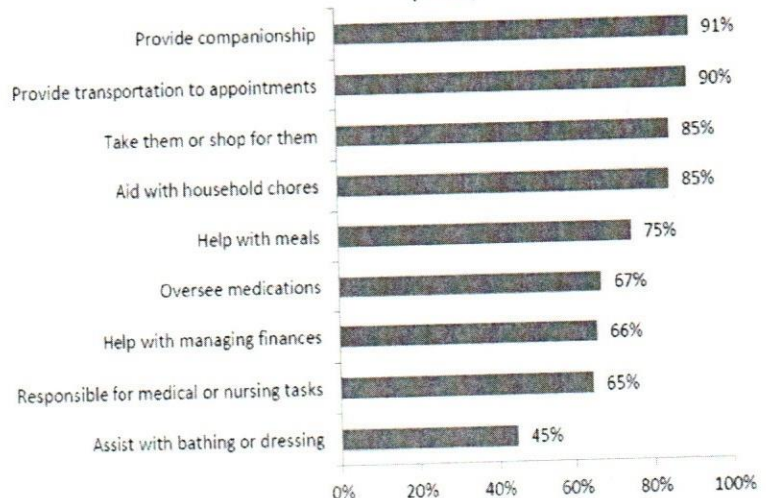
Two in three caregivers reported oversight in medications or responsibility for medical or nursing tasks.

The Emotional Stress of Caregiving (Current & Former Caregivers; n=471)



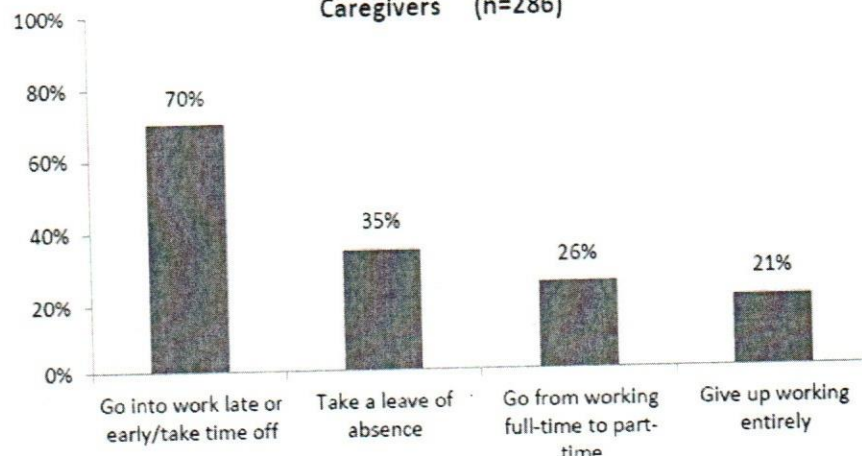
Over 8 in 10 caregivers (82%) reported feeling at least one of the nine stressors that affect their health behaviors, overall health, and financial wellness.

Caregiving Activities of Current or Former Caregivers (n=471)



Work Impacts Experienced by Current & Former Working Caregivers (n=286)

78% of working caregivers have taken at least one of these four actions impacting their work while providing care.



1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Community supports

Participants defined adequate community support with the following statements:

- Adequate services and resources in the community for PWD and caregivers.
- Efforts to do away with the stigma associated with ADRD.
- Knowledge, resources, and support needed are visibly present, and referrals to community supports are made.

Participants reported being unsatisfied with the community support available for caregivers of PWD. They believe the quality of community-based initiatives—such as transportation to access health care services and public preparedness to proactively meet the needs of PWD—could be improved upon.

Much of the community support participants have experienced has been through friends and family, and close-knit community groups that the PWD was involved in prior to being diagnosed.

Community support reported to be already present in some South Dakota communities:

- Ability to take community outings to places that welcome PWD with amenities like family restrooms.
- Parish nurses help keep PWD in the home.
- Exposure to community life is dependent upon the family's willingness to take the patient out. Facilities are limited in their capacity to do so.
- Facilities that support continued engagement in an individual's likes, such as gardening.
- Families come out and support local ADRD efforts.
- Church groups and coffee groups that welcome their friends with ADRD.
- The ministerial associations are supportive emotionally.
- Meals on Wheels keep ADRD patients living at home engaged.
- Some home health agencies will take patients out and about.
- Some facilities try to bring as much community life into the walls, like inviting local schools to perform.

2. Develop funding priorities and strategies to make ADRD services and resources more affordable for facilities to provide and for families to access.

Coverage of costs for services and resources was identified as the most pressing need for persons in South Dakota impacted by ADRD. An ADRD diagnosis affects costs for both facilities and individuals.

For the PWD and their family, the list of costs was described as “overwhelming.” They include primary physician and specialist visits, diagnostic tests, respite care, home health care, long-term facility care, medications, lost wages from caregiving, and even transportation to access services. Participants spoke to how expensive everything about ADRD is and how difficult it can be to find affordable yet quality care options. For some, expense becomes their greatest concern as the disease progresses and a reason for drastic measures to cover costs, such as selling off assets to qualify for long-term care assistance.

Points of greatest frustration:

- Costs are not well articulated. It is difficult to find information on what costs are covered or where to go for financial assistance.
- Strict criteria for financial aid eligibility.
- Adult day and night care and home health are often cost prohibitive.
- Adult day and night care are often not covered by insurance and/or financial aid.
- The care options that are affordable are not always the best quality or provide the level of care the PWD needs, i.e., memory care.
- More expensive care does not equal higher quality or more effective care.
- Limited options for facility placement due to some not accepting Medicaid. If private pay is not an option, families must seek care out of town or out of state.

For long-term care facilities and home health, costs attached to payroll, staff training, and the resources needed to provide the intensive care that PWD require can disable facilities from providing memory care. Low Medicaid reimbursement rates do not incentivize facilities to admit Medicaid patients or provide memory care at all. Participants who work in health care administration said it can be hard to keep the doors open with how low rates are. And as one participant said, memory care facilities that do accept state assistance are “terrible.”

Points of greatest frustration:

- Stagnant Medicare and Medicaid reimbursement. Excess costs are passed on to residents, where the out-of-pocket costs of care exceed the financial means of PWD.
- Cost of memory care—facility, staff, training—far exceeds reimbursement and capacity.

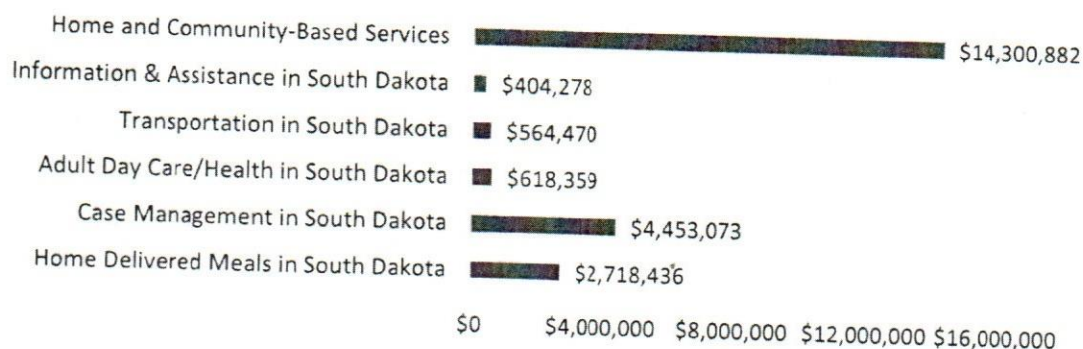
Participants believe funding should support the creation of a model of care that can be easily replicated throughout South Dakota. This model would prioritize affordability, an availability to key resources and services that prioritize the PWD’s quality of life, standardized education and training for all professional caregivers, and guidance and support for family caregivers to effectively navigate their PWD’s journey with ADRD.

What funding for ADRD looks like in South Dakota

State Expenditures

The total projected Medicaid costs for South Dakota adults age 65 and older living with Alzheimer's Disease or other Dementia in 2017 is \$157 million. And is projected to be \$205 million in 2025, a 30% increase in expenditures over the next 8 years. (Source: Alzheimer's Facts & Figures - 2017, U.S. Centers for Medicare & Medicaid Services)

Total Expenditures for the Adult Services and Aging Programs and Services (2015)



Medicaid expenditures by provider type (2016)

Providers with the largest percentage of total Medicaid expenditures in South Dakota in 2016 were hospitals, **nursing homes/assisted living providers**, and Department of Human Services/Developmental Disability community support providers.

South Dakota is an income cap state, meaning that to be eligible for Medicaid long term care benefits there is a hard income limit, no higher than 300% of the Federal Benefit Level of \$2,205/month. (seniorplanning.org, 2017).

Medicaid provides funding for 55% of the individuals in nursing homes. Home and community-based (HCBS) waivers are available and allow Medicaid recipients to receive Medicaid funding for in-home care. Home and community-based services are instrumental to reducing nursing home utilization and improving the quality of independent living for seniors.

HCBS Waiver In-Home Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	414	\$4,072,132	\$820.00
2015	454	\$4,990,267	\$916.00
2016	469	\$5,189,582	\$922.00

HCBS Waiver Assisted Living Services

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	688	\$7,808,825	\$945.84
2015	704	\$8,287,850	\$981.04
2016	686	\$8,376,689	\$1,017.58

Nursing Home Services (DSS only)

State fiscal year	Fiscal year monthly AVG clients	Fiscal year expenditures	AVG monthly expenditure/client
2014	3,332	\$126,812,527	\$3,171.58
2015	3,252	\$136,236,366	\$3,491.09
2016	3,167	\$141,456,793	\$3,722.16

South Dakota Medicaid Report, 2016

How expensive is care?

Adult Day Care	\$68/day
Home Health Aide	\$157/day
Assisted Living	\$3,570/month; average of \$1,150 annual addition for ADRD care
Nursing Home	\$6,300 for semi-private room/month; \$6,813 for private

2017 average rates, Genworth Financials, Inc

Reimbursement rates

"As a professional caregiver, the reimbursement rates in this state have changed immensely. So much so that if you have someone coming in with dementia and someone with a hip fracture, you'll take the hip fracture because the reimbursement rate is so much higher for that person. I know there are facilities doing this on a daily basis. So where do the people go, and what happens to the caregiver, if they stay in the home? I think there is a possibility for people to remain in the home longer, but the resources aren't there because there's limited assistance for that care. There's a huge gap in this state."

3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.

CNA's, home health aides, social workers, and other frontline care workers have more direct contact with PWD and their caregivers than any other health care professions. They are responsible for the intensive, daily, hands-on care PWD require in the home and in a long-term care facility. Participants spoke of a gap between what South Dakota currently has for a health care workforce and what is needed to provide quality care. Despite the essential roles these professions play on the ADRD care team, participants described them as low-pay positions, with minimal ADRD education provided in the workplace, little opportunity for advancement, and high stress. They see these factors contributing to high burnout and turnover rates in the field, which result in inconsistent quality of care and interaction with PWD—factors that can compromise PWD's wellbeing.

If professional caregivers see they are valued through fair compensation for their work and learn how to handle the unique challenges of caring for a PWD better, participants think they may be more inclined to see the value in their work and burnout and turnover rates could be mitigated.

The absence of ADRD specialists and trained physicians throughout most of South Dakota also surfaced during discussion on workforce. There is only one baccalaureate gerontology program offered in South Dakota, meaning that specialty presence in the state is largely dependent upon out-of-state recruitment. This expertise was identified as a need by caregivers who expressed needing professional ADRD or senior care expertise on their side upon diagnosis to help decide the appropriate level of care and for medication management.

Without accessible medical expertise on ADRD, diagnoses have been delayed and in some cases, missed entirely. Delays in diagnosis bring real consequences to the PWD and their family, such as increased difficulty in arranging necessary legal and financial matters, and frustration with handling ADRD symptoms and behaviors without professional guidance or care.

Sioux Falls has the most ADRD expertise within its health care community in South Dakota. Even so, participants see the need for a more ADRD educated and trained workforce. In smaller and rural communities, access channels to specialists that work with ADRD are particularly limited, such as for geriatricians, neurologists, psychiatrists, and primary care physicians with ADRD training. Attempts to rotate specialists amongst rural communities have not met participant expectations and the wait times for primary care and specialist appointments in larger communities have discouraged PWD from accessing care in a timely manner, making a continuum of care experience difficult to realize.

The need for workforce development is statewide. Staffing of facilities is a problem that exists today. With more jobs open than people to fill across many industries—health care in particular—, participants see the demand for workers to staff home health agencies and long-term care facilities well exceeding current capacity. Participants expressed concern as to what this gap in workforce means for South Dakota's aging population in general and ADRD population especially.

Health Care Workforce Current and Projections

In South Dakota, the level of health professional who often cares for older adults and those diagnosed with AD/DR include nurses (RNs), licensed practical nurses (LPNs), certified nursing assistants (CNAs), home-health aides, physicians, nurse practitioners, and physician assistants. Participants refer to them as the *Care Team*.

Home-health aides and CNAs are expected to be among the nation's fastest growing in-demand occupations. The Department of Labor's economists expect about a million more positions will be added from 2014 to 2024. The critical challenge at hand nationally is how to turn these minimum-wage, direct-care jobs into higher-quality and better-paid positions that can attract the millions of new workers who will be needed to meet the demand. (*New York Times*, 2017)

Majority employment settings from January 1, 2015-December 31, 2016

(SD nursing workforce)	RN (17,693)	LPN (2,549)
Hospital settings	48.9%	9.9%
Ambulatory care	13.4%	17.4%
Long-term care	9.1%	29.0%
Community/home health	n/a	10.3%

Estimated Annual Openings, South Dakota (2014-2024)

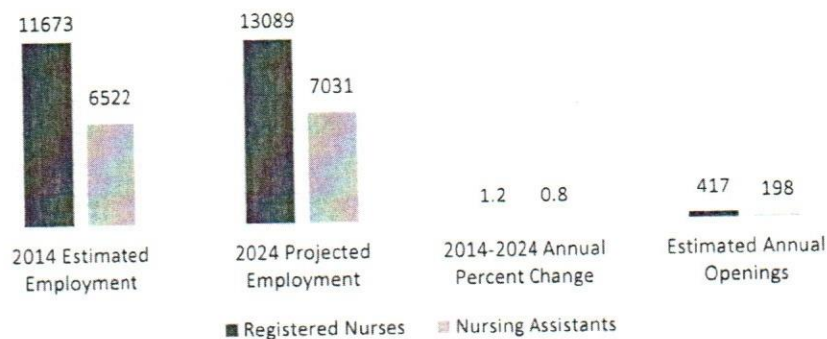
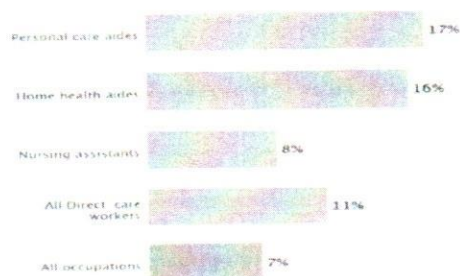


Figure 1 Labor Market Information Center, SD Dept. of Labor & Regulation, 2014

South Dakota: Occupational Growth Projections, 2014-2024



Long-term care projections for the Health Care and Social Assistance Industry show a 10.6% change from 62,395 in 2014 to 68,992 in 2024.

This industry will stand to be supported by technological advancements that may allow more adults to live longer in the home at a lower cost but will not be replaced by increased automation.

South Dakota Health Care Workforce Current and Projections

Primary Care Physicians by Field in South Dakota, Apr-17

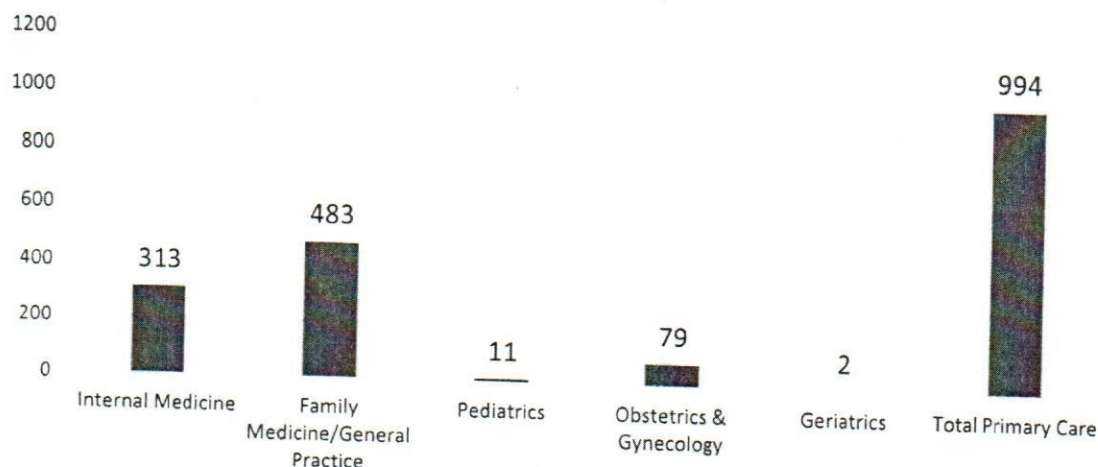


Figure 2: Red-Data, Inc., Special data request on State Licensing Information from Redi-Data, Inc., April 2017. Accessed from the Kaiser Family Foundation website, <https://www.kff.org/state-category/providers-service-use/physicians/>

Gerontology shortfall

With the projected increase in the South Dakota population 65 years of age or older in 2030, an estimated 55,519 (30%) will be most vulnerable. It is projected that 79 Geriatricians will be needed in 2030. Between now and 2030, 65 geriatricians need to be trained to meet the need and gaps in care. Just 6% of the 68 clinical nurse specialists and 1.8% of the 848 certified nurse practitioners practice in Gerontology in South Dakota. (*South Dakota Center for Nursing Workforce, 2017*)

Geriatrician education in South Dakota

- Physician: Geriatrics Program through The University of South Dakota medical school.
- Nursing:
 - Eight baccalaureate degree programs.
 - All include curriculum components guide by the American Association of the Colleges of Nursing, Recommended Competencies and Curricular Guidelines for the Nursing of Older Adults.
 - South Dakota State University undergraduate nursing curriculum include concepts related to neurological changes with aging, including AD/DR.
 - Presentation College includes one theory course on Neurocognitive Disorders, including AD/DR. Students spend at least six clinical hours working with patients in a long-term care or memory unit.
 - Six practical nursing programs.
 - Three associate degree programs.
 - Seventeen approved nursing programs.

National limits on geriatric education include: shortage of time spent in training curriculums, low student demand, and lack of geriatric-trained educators. (*Bardach, S. H., & Rowles, G. D. (2012). Geriatric Education in the Health Professions: Are We Making Progress? The Gerontologist.*)

4. Prioritize the education and training of professional care providers and family caregivers to improve care quality and efficiencies.

43.2% of survey respondents identified the education and training of health care professionals and caregivers as one of the most pressing needs for persons impacted by ADRD in South Dakota. In all fifteen focus groups, education and training—or lack thereof—was spoken of critically in the following ways:

- Why it is important to have a state plan on ADRD.
- Service or resource missing that would improve care.
- Significant barrier to access services/resources.
- A point of significant value when shown.
- Recommendation for improving the care of PWD in South Dakota.

Participants believe that health professionals at all levels of care are unprepared to address ADRD- and resort to guessing much of the time. Whether it is the primary physician that addresses the first symptoms and diagnosis of ADRD, or the CNA or home health aide that is responsible for comfort care and behavior management as the disease progresses, participants are not confident in the level of education and training professionals possess. Participants who identified as health professionals working in the field of ADRD expressed doubt of their own care competencies and called for additional training through the workplace to become more adept for the sake of quality patient care and career longevity.

Participants recognize the complexity and difficulty of providing ADRD care and propose a concentrated, ongoing ADRD curriculum that equips care providers to be competent, agile, and able to meet PWD and their caregivers where they are at.

Participants also called for professions that have a more indirect connection to PWD—dentists, optometrists, pharmacists, financial advisors, lawyers—to at the very least be able to recognize symptoms and appropriately work with PWD. Training would include how to respond and adjust to uphold the safety, dignity, and best interests of PWD.

Family caregivers also need education and training. Participants who identified as family caregivers shared that they knew very little themselves and were educated very little upon diagnosis. They reported trouble in determining how best to care for the PWD in the home, when/if to transition to a long-term care setting, and how to make use of limited community services. They did not know enough to make informed care decisions in the PWD's best interest. They were unprepared to handle the emotional, financial, and physical toll of caregiving. Without proper education and training available, the PWD under their care is not able to thrive to the best their condition allows. And caregivers report exhaustion and a decline in the quality of their own lives. 41.5% of survey respondents noted that caregiver education and training were the most helpful resources available to them. Financial support for caregivers to get the training they need was identified as a significant need.

In addition to improving the quality of ADRD care and reducing frustration of professional and family caregivers, participants see increased education and training as a critical means to slow disease progression and extend a PWD's quality of life. An ADRD competent caregiving community can lead to an increased rate of early diagnosis, appropriate care intervention, and help to minimize stigma by increasing awareness and understanding.

Participant input on ADRD education and training in South Dakota

Participants set the priority of developing standardized education and training for professional and family caregivers. Education and training were top of mind for participants and discussion surfaced many recommendations as to who should be educated and trained, who should be responsible for its delivery, how it could be offered, and topics that need to be covered. The following are recommendations and ideas that were mentioned in two or more focus groups and in survey responses.

Who should be educated?

Patients	Students	SD politicians and legislators
The public/community	All care workers (CNAs to MDs)	Specialists
Families	Hospital/facility administrators	All who work with ADRD
Caregivers		

Who should be responsible for education and training?

Senior centers	Physicians	Professional ADRD Educator
Churches	Long-term care facilities	Middle & high schools
Clinics	Government	Colleges and universities
Alzheimer's Association	Home health agencies	

Modes of delivery

Alzheimer's Association	At the time of diagnosis	Distribute online
Take-home reading material	Through the workplace	Annual ADRD state conference
Local educational events	Care provider's offices	Concise and clear information
Seminars for professional and family caregivers	Mandatory continuing education credits	Centralized place to go to find resources and services

Education and training topics for families/family caregivers:

Caregiving techniques	Progression of the disease/what to expect
Safety measures	How to manage challenging behaviors
What to do first	Recognition of the disease; early indicators
How to cope with the stressors of caregiving	Where to go for education and support
How to access services and resources	Creative care solutions
Associated financial and legal matters	Hand-in-Hand training through CMS

Education and training topics for professional caregivers:

Manage behavioral issues and crisis response	Care options; home health or facility placement
How to effectively interact with PWD	Difference between ADRD resident & general pop
How to best communicate with families	ADRD is not a normal part of aging
Diagnostic training on all types of dementia	Alternative therapies
Pharmacology/medication management	Available community resources and referrals

Participants did not focus on strategizing how to bring increased education and training to South Dakota, but did emphasize that it must be easily accessible, well-publicized, and affordable to be effective on a statewide scale and bring about a meaningful improvement in the quality of care provided.

5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

Survey respondents rated their satisfaction with public awareness a 2.7 (on a scale of 1-5) with room for improvement. Throughout focus group discussion, the call for increased community awareness and support was framed as a way reduce the stigma attached to ADRD in South Dakota and open the issue up for expanded discussion at all levels: in the home, in the community, and at the state level.

ADRD stigma can be seen in many ways:

- Individuals are reluctant to acknowledge memory concerns and related symptoms.
- Families are embarrassed and/or afraid of an ADRD diagnosis.
- Family caregivers do not want to accept help and are slow in doing so.
- Physicians delay evaluation/diagnosis.
- Home health is not touted as a viable, long-term care option.
- Long-term care facilities are ill-equipped to provide the type of care PWD need.
- Community services and resources are not well-known or sufficient.
- The public chalks it up to “old age.”
- State Officials have not prioritized the condition of ADRD, its diagnosis, or its care even though education opportunities exist annually during session and throughout the year.

Stigma—matched with a lack of public awareness and support—can be detrimental for PWD and their families and allows the disease to grow behind closed doors. Participants see an increase in public awareness and support as an essential part of improving the care of PWD in South Dakota and improving their overall quality of life.

With more awareness comes a larger network of support to aid in the care of PWD and reduce the burden on both family caregivers and the health care community.

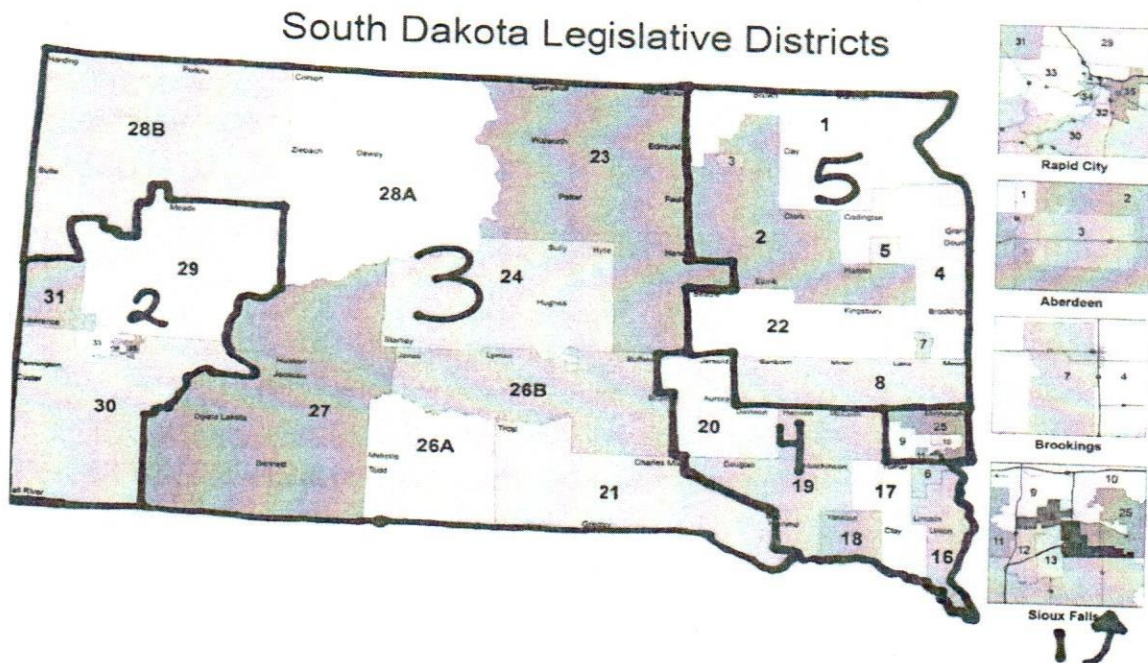
Looking forward, participants want South Dakota to understand ADRD and rally behind it by endorsing the need for public awareness and support.

“One client told me, ‘this is embarrassing, I wish I had cancer.’ With other diseases, people wear pink and fight for the cause, but with this disease, people leave town, so no one has to see them with this disease. We don’t have awareness or a road map for how this disease will progress and that can be scary.”

Focus Group Findings by Region

Region 1.....	34
Region 2.....	35-36
Region 3.....	37
Region 4.....	38
Region 5.....	39

South Dakota divided into five regions by legislative districts



REGION 1 FINDINGS: Encompassing the counties of Minnehaha and Lincoln.

Focus groups conducted in Sioux Falls and Brandon.

ADRD services and resources exist in Region 1. There just needs to be more of them with better access and a more competent workforce.

- When asked to name care facilities available for PWD in the community, participants listed off facilities that are either memory care exclusive or that offer a memory care unit. This speaks volumes as to what is already available in Region 1 for care facilities.
- As ADRD prevalence grows throughout the state, it will be important that additional adequate and affordable quality memory care be available in these highly populated communities.

Frustration exists in the ADRD community as to how professional care looks like today.

- There are too many barriers to accessing services and resources. The lack of knowhow amongst care professionals, the stigma, and high costs for all ADRD care types prohibit PWD and their caregivers from finding the best care possible.
- Family caregivers and PWD advocates do not see enough of a concentrated focus on what makes ADRD care different than general care or other specialized care disciplines, including how best to respond to the unique needs of PWD and honor the role and needs of family caregivers.
- Training and education for all care professionals who touch ADRD is needed. Everything from the basics—what ADRD is—to the more complex—handling behaviors, crisis response, alternative therapies. Education and re-education was called for to increase the competency of professionals working with PWD and improve upon how ADRD is managed in the health care experience.

Region 1 sees an ADRD state plan as an advocacy tool that could help PWD and caregivers get the care they need and deserve.

- ADRD is complex and requires adequate community support to improve the delivery of care. Top of mind is addressing the stigma that surrounds ADRD. With increased awareness and comfort comes better care and quality of life for PWD.
- The critical need for education and training for professional and family caregivers is a safety issue for PWD that can be brought to light through a state plan.
- A state plan can show why ADRD is important for South Dakota to address and how to most efficiently and consistently provide needed care and resources throughout the state.
- Easy access to information that helps caregivers find services for PWD and respite services for themselves, could be met if recognized in a state plan.

REGION 2 FINDINGS: Encompassing the counties of Custer, Fall River, Lawrence, Meade, and Pennington.

Focus groups conducted in Rapid City and Spearfish.

What currently exists for services and resources is inadequate throughout the region.

- Assisted living and nursing homes with memory care units exist but not on the scale that is needed to meet growing demand.
- Many assisted living, skilled nursing facilities, and home health agencies who serve PWD do not feature any memory care and are not designed to address agitation and other ADRD behaviors.
- Availability of primary and specialty physicians is low, causing long wait times for referrals, diagnosis, and treatment.
- Caregivers desire expanded access to adult day services, support groups, education, training, and continuous guidance.
- West River is limited on services and resources for higher acuity PWD. Behavioral health and crisis intervention is virtually nonexistent.
- Understaffing at care facilities compromises consistency in seeing the same care providers once a care plan is established.
- ADRD education and training is lacking for professional and family caregivers. This proves to be a barrier for family members trying to access services and resources and compromises the competency of care provided.
- When a service or resource is identified, it is often cost prohibitive, difficult to navigate within and between, and marked with limited quality assurance.

The ADRD care team includes family caregivers, family and friends, and the community. Each group should be incorporated and supported in the care of PWD.

- There is a lack of coordination, evaluation, and planning amongst ADRD services and resources.
- Caregivers lack education, support, and knowhow.
- Family members would like to be included in care plan development and implementation, at home and in a care facility.
- With increased community involvement comes increased visibility of ADRD and the potential to reduce the stigma around ADRD. Involving the likes of first responders, lawyers, financial advisors, and senior centers can improve care and increase awareness.

REGION 2 FINDINGS continued: Encompassing the counties of Custer, Fall River, Lawrence, Meade, and Pennington.

Focus groups conducted in Rapid City and Spearfish.

Improving the state of care and resources for PWD will require the attention of South Dakota lawmakers.

- The increasing prevalence of ADRD calls for action on the state level to make sure it is dealt with appropriately.
- A state plan developed from the statewide needs assessment can best articulate what the needs of PWD and their caregivers are and direct the distribution of services and resources to communities throughout the state.
- With a state plan there can be mandatory ADRD training for diagnosing physicians and other frontline care providers in South Dakota.
- Lawmakers can provide the resources and direction needed to increase the number of assisted living and nursing home beds with memory care so that PWD can access the level of care they need close to home, when they need it.
- Lawmakers can ensure a focus on resource and service development for PWD and their caregivers throughout rural West River. They can influence how best to get care to those who need it, whether it is through hosting small facilities or satellite offices in rural areas or exploring the role telemedicine could play.
- Lawmakers make it affordable and convenient to disburse.

REGION 3 FINDINGS: Encompassing the counties of Bennett, Brule, Buffalo, Butte, Campbell, Charles Mix, Corson, Dewey, Edmunds, Faulk, Gregory, Haakon, Hand, Harding, Hughes, Hyde, Jackson, Jones, Lyman, McPherson, Mellette, Oglala Lakota, Perkins, Potter, Stanley, Sully, Todd, Tripp, Walworth, and Ziebach.

Focus groups conducted in Pierre, Chamberlain, and Mobridge.

Limited services available in Region 3, especially outside of Pierre.

- Care facilities—assisted living and skilled nursing—are scarce. Participants identified two memory care facilities available in Pierre and just one memory care unit in Mobridge. Regional hospitals were noted as the main service providers for PWD.
- Caregiver support—adult day services, home health, and support groups—were reported to be limited. In a region with limited services and resources, one participant said that a support group became the biggest asset she had.
- Region 3 could benefit from having increased caregiver support services, including education and training.
- There are not enough employees or enough dollars to staff care facilities and home health agencies.

Region 3 is not connected to ADRD. ADRD knowledge, resources, and support are not present or visible.

- There is a lack of ADRD educated and trained care providers, from CNA's to physicians.
- Care providers simply do not understand ADRD. Diagnosis and symptom awareness are not adequately addressed in the health care experience.
- PWD and their care providers feel they are on their own. There is not a hub for ADRD care, some places do not even have access to services like telemedicine. There is little acceptance that ADRD is a reality. People don't know where to go or what to do for care or support.
- Participants define adequate community support as having both access to care and services and people feeling comfortable and knowledgeable enough to seek them out. Neither is a reality.

REGION 4 FINDINGS: Encompassing the counties of Aurora, Bon Homme, Clay, Davison, Douglas, Hanson, Hutchinson, Jerauld, Lincoln, McCook, Turner, Union, Yankton.

Focus groups conducted in Yankton, Vermillion, and Mitchell.

Facilities to serve PWD exist, but supply does not match demand.

- Facilities are generally understaffed.
- Staff working in these facilities are generally poorly trained.
- Most lack specialty services, such as geriatric psychiatry.
- There is rarely enough space to accommodate onsite independent/transitional living.

Caregivers drive decision making.

- The caregiver is often the first to identify a change in behavior that leads to diagnosis.
- Caregivers lack the knowledge, resources, and support network to adequately meet the needs of their loved ones with ADRD.
- An ADRD diagnosis negatively impacts a caregiver's well-being and quality of life.

Living in a rural setting is a barrier to accessing needed information and services.

- All needs associated with ADRD are compromised in a rural setting.
- Whether specific to specialty services, transportation, sufficient workforce, adequate facilities, caregiver support, stigma resistance, funding, or education/information, access to resources is significantly compromised in a rural setting.

REGION 5: Encompassing the counties of Beadle, Brookings, Brown, Clark, Codington, Day, Deuel, Grant, Hamlin, Kingsbury, Lake, Marshall, Miner, Moody, Roberts, Sanborn, Spink.

Focus groups conducted in Aberdeen, Watertown, and Brookings.

ADRD services and resources are limited by insufficient workforce numbers, high costs of providing care, and a lack of education and training.

- Memory care facilities and units in assisted living and nursing home facilities exist throughout the region but do not meet the demand.
- Caregiver support—adult day services, home health, and support groups—exists on a limited scale. An increase in caregiver support was identified as a way to improve care.
- There are not enough workers for ADRD service and resource providers to hire to adequately staff their operations. Finding qualified and certified staff is just as difficult.
- Training and education is lacking across all care provider groups—family caregivers, professional caregivers, and indirect care professionals, including police and emergency medical technicians (EMTs).
- Everything related to ADRD care, in the home or in a facility, is too expensive for facilities and families to bear without assistance. If private pay is not feasible for families, their options are significantly reduced. If reimbursement rates do not help cover costs, facilities are not incentivized to provide services or to expand service.

ADRD is not met with the proper support in Region 5.

- There is a lack of ADRD educated and trained care providers, from CNAs to physicians.
- Care providers are unskilled in diagnosing and handling ADRD, making the creation of and adherence to an effective care plan nearly impossible.
- Region 5 is made up of many small communities that either do not have access, or have inconsistent access, to specialty care providers and support services such as geriatricians and behavioral health specialists. This limited access is compounded in the surrounding rural communities.
- Participants do not believe there is adequate community support of ADRD. Resources in larger communities are not funneled to smaller communities. Any resources and support are not visible, and little is being done to do away with the stigma surrounding ADRD.

Recommendations and Strategies

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Matching Strategies to Meeting the Needs of PWD and their Caregivers

1. Ensure quality services and resources are available to PWD and their caregivers in rural and urban settings.

Rationale: ADRD is associated with intensive use of services and resources over what can be a long disease course. South Dakota does not have the health care infrastructure or community supports in place to meet the needs of PWD and caregivers. When a more comprehensive and inclusive system is in place for service and resource delivery, the entire state will benefit.

Suggested strategies:

- Readdress the moratorium on nursing home beds for South Dakota. Make sure bed distribution is balanced by need and projected demand.
- Prioritize PWD's quality of life by making memory care the option for PWD, through an increase in memory care facilities and by advocating for nursing facilities to adopt memory care best practices in general population settings.
- Expand home health and community-based services to keep PWD in their homes longer to cut costs for families and the state.
- Establish a single point of entry system for PWD supported by patient navigators to ease access to information, health care services, and caregiver support services.
- Create a centralized point of information for—and access to—services and resources.
- Use technology, like telemedicine, to extend the reach of services and resources in South Dakota, better administer timely care, and reduce costs.

2. Develop funding priorities and strategies to make ADRD services and resources more affordable for facilities to provide and for families to access.

Rationale: It was determined that financial assistance and relief will be necessary to assure all South Dakotans diagnosed with ADRD receive adequate and appropriate care.

Suggested strategies:

- Establish family-caregiver funding at the state level. It is more cost efficient to keep PWD in the homes versus in a facility. This funding would be to make adult day services and in-home care more affordable and support family caregiver education and training.
- Pursue third-party reform and reimbursement at all levels, including for home health care.
- Expand Medicaid and increase reimbursement rates to improve the overall quality of care in a facility, and to help cover payroll and ADRD training costs for facility staff.

Matching Strategies to Meeting the Needs of PWD and their Caregivers

3. Execute the necessary steps on state and local levels to develop an adequately sized and skilled ADRD workforce throughout South Dakota.

Rationale: An adequately sized, educated, and trained workforce is needed to uphold South Dakota's current slate of ADRD care offerings and the industry's projected growth alongside the projected increase in ADRD prevalence in the state.

Suggested strategies:

- Professionalize the Certified Nursing Assistant (CNA) position and other formal caregiving positions to increase field numbers and show the economy values them.
- Create an ADRD certification for health care workers to attain and for home health agencies and long-term care facilities to recognize within their pay structures.
- Determine how many health care workers will be required to meet projected demand for ADRD care in South Dakota. Identify how this workforce can be cultivated within the state and how universities can play a part.
- Increase Medicaid reimbursement rate for long-term care facilities to support increasing staff pay using new standards. Increase reimbursement rates to home health agencies.
- Invest in staff. Identify leadership and professional growth opportunities.
- Attract and recruit more ADRD specialists to South Dakota and establish access channels to rural and small communities. Incentivize professionals choosing a rural work environment.

4. Prioritize the education and training of professional care providers and family caregivers to improve care quality and efficiencies.

Rationale: Standardized, affordable, and conveniently accessible education and training creates consistency in the quality of care received across care provider roles, settings, and geographic locations.

Suggested strategies:

- Educate and train all professional caregivers in residential and home care settings as well as family caregivers so they can provide and direct to the best care possible.
- Pursue the most effective mode of education and training delivery for each target audience and topic. Consider distribution through the Alzheimer's Association, workplaces, online platforms, and local events.
- Develop separate curriculums for family caregivers and professional caregivers to better equip each group to be successful in their environment.
- Standardize education and training in South Dakota and make it a requirement for all professional caregivers in the field. Support this initiative with state funding.
- Prioritize efficient and accurate diagnosis of ADRD with a built-out referral system in which care providers know what is available to their patients and from whom.

Matching Strategies to Meeting the Needs of PWD and their Caregivers

5. Reframe how ADRD is understood, seen, and cared for throughout South Dakota to reduce stigma and improve the quality of life a PWD experiences.

Rationale: When ADRD becomes a topic that people are familiar with and comfortable addressing—personally, professionally, or in the community—PWD and their caregivers are more likely to seek out and find the care they need, and the care they ultimately receive will be of higher quality than when the disease is hidden. With exposure comes attention and action.

Suggested strategies:

- Identify a champion to stand behind the cause and generate statewide attention.
- Answer the *why* for each industry to care about ADRD for the sake of business—their employees and customers.
- Develop awareness tactics. Use public service announcements, local TV and radio, radio, and the internet.
- Make sure the knowledge, resources, and support needed are visibly present to all involved with ADRD.
- Design places and host groups that welcome and cater to PWD and their caregivers, such as memory cafes, family bathrooms, and support groups.
- Create a platform for caregivers—family and professional—to share experiences and collaborate on what works best.
- Make the Alzheimer's Association South Dakota Chapter and local councils' efforts visible and invite the community to get involved.

Improving Support and Resources by Region

Region 1 | Opportunities to improve support and resources to PWD.

- Identify how efforts at the state level can increase the ADRD care workforce. A need for more CNAs could be met with an increase in wage through an increase in state reimbursement for care facilities or establishing a certification for ADRD skilled facilities and staff.
- Pursue third-party payer reform and reimbursement at all levels, including home care. Also consider family caregiver funding at the state level.
- Create a continuum of care for PWD.

One strategy to be successful: *"Make it a community effort. Incorporate and address the challenges of professions impacted by ADRD and then identify how they can all contribute."*

Region 2 | Opportunities to improve support and resources to PWD.

- Increase the number of assisted living and nursing home beds with memory care so that PWD can access the level of care they need close to home, when they need it.
- Focus on resource and service development for PWD and their caregivers throughout rural West River. Consider how best to get care to those who need it, whether it is through hosting small facilities or satellite offices in rural areas or exploring the role telemedicine could play.
- Create mandatory ADRD training for diagnosing physicians and all other frontline care providers in South Dakota. Make it affordable and convenient to disburse.

One strategy to be successful: *"Mindset is important. Consider what you would like to see for our own family. What do you want available when ADRD comes to your home?"*

Region 3 | Opportunities to improve support and resources to PWD.

- Identify champions amongst community and regional leaders who can bring impact to the things they rally behind. Increasing public awareness will help decrease stigma.
- Restructure existing facilities to be better equipped in meeting the needs of PWD. Increase memory care options throughout the region.
- Establish a state-supported online platform for PWD and family caregivers to have access to physicians and specialists. Technology could help bridge distance and stigma.
- Increased reimbursement, workforce development, and the development of an ADRD skilled workforce are important in working towards meeting the needs of PWD.
- Focus on educating legislators about the need for accessible and affordable education and training.

One strategy to be successful: *"Stay engaged and follow up with all the entities around the state because things can change quickly."*

Improving Support and Resources by Region

Region 4 | Opportunities to improve support and resources to PWD.

- Develop certification criteria for facilities and staff who work with PWD. Motivate certification achievement with financial allocation ratios directly correlated to levels of achievement. Certifications can be for education/training achievement by individuals and for achieving standards of care, providing specialty services, etc. for facilities.
- Develop a statewide public awareness campaign dedicated toward the caregiver. Emphasis symptom awareness, access to resources, defining what a caregiver is. Incorporate general awareness information to address stigmas around ADRD.
- Incentivize the start, addition or expansion of facilities in communities of fewer than 5,000 population from an economic development mindset to ensure enough access to resources.

One strategy to be successful: *"Read the study!"*

Region 5 | Opportunities to improve support and resources to PWD.

- Expand the ADRD care team to include physicians, nurses, CNA's, pharmacists, first responders, state workers, and those in the financial and legal aid professions to cover all needs of PWD. Prioritize education and training with this group.
- Advocate for a person-centered care model of care that prioritizes PWD's quality of life and that involves their family when appropriate.
- Host a statewide conference or educational retreat focused on ADRD for professional and family caregivers. Include presentations and learning opportunities from and for the expanded care team.
- Create an ADRD certification for care providers that employers could recognize in their pay scale.
- An ADRD certification for pharmacists, first responders, and those in the financial and legal aid professions could be promoted as a differentiator and as an ADRD-friendly partner.
- Make it possible for ADRD care facilities and agencies to thrive in small communities through increased reimbursement rates and making what is available for services widely known.

One strategy to be successful: *"Create an advisory committee that is assigned with manageable, incremental goals and held accountable to meaningful progress."*

How the Work Group can be Successful

"How do we get everybody else to feel how we feel; see how big the issue is? That this work is not an option."

Key issues to prioritize and work through:

- Funding on the state level through Medicaid reimbursement and expansion.
- How to increase capacity to handle higher-acuity PWD in assisted living settings.
- Respite care.
- Workforce development.
- What does a continuum of care look like?
- What does comprehensive care mean for SD?
- Accessibility and affordability of resources and services for patients and caregivers.
- Assure transportation is available.
- Better training and education for all direct care providers.
- Dollars to support an adequate and well-trained workforce.
- Reallocation of funding to support patients and caregivers.
- How will the Native American population be served?
- What a centralized, well-known spot for families and doctors to go to for answers looks like.
- Ease of access.
- How does prevention fit in?
- How to capture a person at the point of diagnosis.

Strategies to be successful:

- Bring Sanford and Avera into the conversation.
- Identify an advocate in each community.
- Invite legislators to visit all levels of care facilities.
- Get good Public Relations around it so people feel more comfortable talking about it.
- Solicit information from CNA's, nurses, and others on the frontlines.
- Use what is working in other state plans.
- Have a Plan B for higher-acuity PWD.
- Make it a community effort. Incorporate and address the challenges of professions impacted by ADRD and then identify how they can all contribute
- Stay engaged and follow up with all the entities around the state because things can change very quickly.
- Mobilize our grassroots system. Greatest impact is achieved when churches are involved and can get the credibility by tapping into the resources that are already built.

How the Work Group can be Successful

Things to keep in mind:

- Urgency. It is not going away. Look at statistics of prevalence.
- Economic development opportunities exist.
- Scalability.
- Patient dignity and respect.
- South Dakota is rural state. What works for Sioux Falls will not work in Platte.
- Give a voice to those who cannot otherwise have their voice be heard.
- Needs to be as current as possible and continuously updated.
- Pierre recognizes the problem, but they are not exactly sure what to do with it. If there are ways that the private sector can help with that, they should be included.
- Money cannot always follow service statistics. Some things cost more in rural communities.
- Investing in adult day care and other caregiver respite services would save the state a lot of money.
- Traditional behavioral crisis resources should not be used for PWD who have behavioral problems.
- High percentage of people in nursing homes with second highest occupancy of licensed beds, which means a high waiting list.

